



Fetal Alcohol Spectrum Disorder in Nevada:

FASD Town Hall Meeting Summaries and Recommendations

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Fetal Alcohol Spectrum Disorder in Nevada:
FASD Town Hall Meeting Summaries and Recommendation

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This report summarizes the public testimony shared by parents, individuals, medical, nursing, and social service professionals affected by fetal alcohol spectrum disorders. The recommendations in this report are based on that testimony, and are a collaborative effort of the Bureau of Family Health Services and the Perinatal Substance Abuse Prevention Subcommittee of the Maternal and Child Health Advisory Board.

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And finally, to the professionals and families who attended these Town Hall Meetings, shared their concerns and experiences, and committed with us to preventing FASD, and to meeting the needs of individuals—across their life span—with an FASD.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	PAGE 6
FETAL ALCOHOL SPECTRUM DISORDER.....	PAGE 10
NEVADA'S TOWN HALL MEETING	PAGE 14
DEFINING ISSUES	PAGE 17
RECOMMENDATIONS	PAGE 30
APPENDICES	PAGE 33

EXECUTIVE SUMMARY

In January 2006, the Perinatal Substance Abuse Prevention Subcommittee of the Maternal and Child Health Advisory Board coordinated and hosted two Town Hall Meetings dedicated to the issue of Fetal Alcohol Spectrum Disorders (FASD). The testimony heard in Las Vegas and in Reno is summarized in this report. The report also suggests some barriers to services for individuals with an FASD and some communities in need of training and outreach; it concludes with recommendations for addressing these issues.

MISSION STATEMENTS

Under NRS442.133, the Maternal and Child Health Advisory Board was appointed by the Governor to advise the Administration of the Health Division on matters concerning perinatal care to enhance the health and survivability of infants and mothers, and on matters concerning programs designed to improve the health of children. Specific provisions are made within this statute to reduce the incidence of preventable diseases and handicapping conditions among children, which is addressed specifically by the Perinatal Substance Abuse Prevention Subcommittee.

Statutory changes to NRS 442.137 now include language mandating the identification of the most effective methods of preventing fetal alcohol syndrome and collecting information relating to the incidence of fetal alcohol syndrome in this state; prevention of the consumption of alcohol by women during pregnancy; assisting the Health Division to develop and carry out a program of public education to increase public awareness about the dangers of fetal alcohol syndrome and other adverse effects on a fetus that may result from the consumption of alcohol during pregnancy; and, assisting the University of Nevada School of Medicine in their development of guidelines to assist health care providers with pregnant women who are at a high risk of consuming alcohol during pregnancy; and children who are suffering from fetal alcohol syndrome.

The mission of the Nevada State Health Division, Bureau of Family Health Services is dedicated to improving the health of families, with emphasis on women, infants, and children, including children with special health care needs, by promoting, assuring, and providing health education, prevention activities, quality assurance and assuring access to health services. It promotes and insures services are coordinated, family-centered, community-based, comprehensive, and culturally competent.

FETAL ALCOHOL SPECTRUM DISORDERS

Fetal Alcohol Spectrum Disorder is an umbrella term, used to describe a spectrum of diagnosable disorders effecting individuals who were prenatally exposed to alcohol. Often “invisible” to the public, these may be physical, mental, behavioral, and learning disabilities. FASD refers to conditions such as: **Fetal Alcohol Syndrome (FAS)**, **Partial Fetal Alcohol Syndrome (PFAS)**, **Fetal Alcohol Effects (FAE)**, **Alcohol-Related Birth Defects (ARBD)** and, **Alcohol-Related Neurodevelopmental Disorder (ARND)**.

National experts tell us that the birth of children with FAS is more frequent than “spina bifida, Down syndrome, and muscular dystrophy combined. *FASD*, including FAE, ARBD, and ARND,

occurs even more often.”¹ Nevada may be at heightened risk for resident children born with an FASD.

Children with an FASD suffer with this disability across their life-span. In addition to related health problems, they often experience decreased intellectual functioning, deficits in verbal learning, spatial memory, and reasoning, cognitive motor deficits, slowed reaction time, and balance problems.²

Experts from the *Centers for Excellence on Fetal Alcohol Spectrum Disorder* estimate the lifetime health costs for individuals born with FAS at \$860,000, and the reduced lifetime productivity, lost wages, and subsidies at an additional \$200 thousand. These experts argue “even ‘expensive’ FAS prevention may be cost effective up to \$850,000 per child.”³

TOWN HALL MEETINGS

The Town Hall Meetings were attended by seventy-eight participants; eighteen provided testimony. Participants included:

- ✓ Seven parents (all either foster- or adoptive parents), and one adolescent with an FASD,
- ✓ Twenty-one health care professionals,
- ✓ Eleven social workers,
- ✓ One representative from a Nevada School District,
- ✓ And, three state leaders from the Senate and/or judiciary.

State agencies and organizations represented include: The Bureau of Family Health Services, Court Appointed Special Advocates, Friends of Special Children, Washoe County Social Services, Division of Mental Health and Developmental Services, the University of Nevada School of Medicine, Washoe County District Health Department, Nevada State Welfare Division, Clark County School District, Nevada Early Intervention Services, the Division of Child and Family Services, and the Nevada State Senate.

Testimony suggested the following as “Defining Issues” for our continued work:

- ✓ Allied professionals lack education, sympathy, and effective involvement;
- ✓ Individuals with an FASD, and their families, are isolated from support communities and resources;

¹ *Starting the Conversation: Town Hall Meetings on Fetal Alcohol Spectrum Disorder*. SAMSHA Fetal Alcohol Spectrum Disorders Centers for Excellence. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration: April 2004.

² Ibid.

³ Harwood, Henrick. “Economic Costs of Fetal Alcohol Syndrome.” The Lewin Group: Fairfax, VA 2003.

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- ✓ Almost universally, individuals experience challenges and delays in accessing a “diagnosis;” there are few, if any, appropriate services and resources specific to the needs of individuals with an FASD;
 - ✓ Foster- and Adoptive-Parents assume an unmitigated burden in caring for children with prenatal exposure to alcohol; and
 - ✓ Adolescents and adults with and FASD are eligible for few, if any, appropriate supportive and transitional services to assist in independent living.

The Perinatal Substance Abuse Prevention Subcommittee has agreed on the following policy recommendations and priorities based on issues raised in public testimony:

- ✓ Implement Training and Outreach Programs, and provide “Best Practice” recommendations to Nevada’s Health Care Community, School Districts and Bureau of Early Intervention Services, Criminal Justice systems, state-funded child care providers, and transitional, vocational, residential and social service programs serving the disability community.
- ✓ Create, train, and support an FASD advocacy corps in efforts to enter a variety of systems (at the request of parents/individuals with an FASD) to advocate for informed, lawful, and appropriate system’s responses to individuals with an FASD. Systems advocacy and influence should include school districts, Early Intervention, criminal justice, transitional and vocational programs, and social service programs.
- ✓ Fund and train social workers to function within Welfare, Medicaid, and judicial systems as FASD case managers.
- ✓ Pass amended statutes requiring child welfare agencies and other licensed child placement agencies to investigate the likelihood of prenatal exposure to alcohol and other drugs.
- ✓ Create fellowships for geneticists, pediatricians, and child- and adolescent-psychologists to do rotations with Special Needs children; hire and support the community work (diagnostic assessment) and research of geneticists.
- ✓ Encourage or require state systems of care across the life-span to recognize FASD as a disability.
- ✓ Promote legislative allocations of seed monies for three separate projects:
 - creation and support of a statewide non-profit whose mission would be to establish an advocacy and education center;
 - a pilot project, with outcome measures, which creates a “center” for FASD Family Services, including assessment and diagnosis, prevention campaigns, referrals and family parenting plans, and training and technical assistance to para-professionals;
 - a pilot program which works purposefully with children with an FASD, and whose outcomes and experience can be used in the creation and mentoring of other child care programs; and

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- the creation and support of FASD Campus for adolescents and adults, where “students” could learn life- and job-skills toward independent living.
 - ✓ Coordinate a prevention campaign which includes women of child-bearing age, the health care community, Family-Planning organizations, pharmacies (where contraception is sold), and high-risk populations (including mothers who’ve already given birth to children with an FASD).

FETAL ALCOHOL SPECTRUM DISORDER

Fetal Alcohol Spectrum Disorder is an umbrella term, used to describe a spectrum of diagnosable disorders effecting individuals who were prenatally exposed to alcohol. Often “invisible” to the public, these disabilities may be physical, mental, behavioral, and learning. FASD refers to conditions such as:

- ✓ **Fetal Alcohol Syndrome (FAS)** Children with FAS have characteristic facial features, growth deficiencies, and neurologic damage. Over time, individuals with FAS may have decreased intellectual functioning, deficits in verbal learning, spatial memory, and reasoning, slowed reaction time, balance problems, and motor deficits.
- ✓ **Partial Fetal Alcohol Syndrome (PFAS)** Children who have only two of the three characteristics of FAS (facial features, growth deficiencies, and neurologic damage) are diagnosed with PFAS.
- ✓ **Fetal Alcohol Effects (FAE)** The term has been used in referring to children with all signs of FAS except the characteristic facial features.
- ✓ **Alcohol-Related Birth Defects (ARBD)** Children born with ARBD may have all signs of FAS, but also have malformations in the skeletal and major organ systems.
- ✓ **Alcohol-Related Neurodevelopmental Disorder (ARND)** The diagnosis is used in the absence of FAS physical features, but the presence of central nervous deficits.⁴

The incidence rate for FAS—a completely preventable birth defect—in the United States is estimated between .05 and 3 per 1,000 live births. National experts tell us that the birth of children with FAS is more frequent than “spina bifida, Down syndrome, and muscular dystrophy combined. *FASD*, including FAE, ARBD, and ARND, occurs even more often.”⁵

Nevada may be at heightened risk for resident children born with an FASD. Dr. Colleen Morris, a Nevada geneticist, commented that as a medical student she was taught that FAS was rare, occurring in 1 of every 600 live births (equivalent to Down Syndrome). When she began her work in Nevada in 1988, she saw FAS at three times that rate; she now sees the occurrence of FAS at ten times that rate.⁶

Just why this incidence rate is seemingly higher in Nevada is not entirely clear, and merits attention. Prevention experts seem unified in their beliefs that a significant number of mothers who expose

⁴ *Starting the Conversation: Town Hall Meetings on Fetal Alcohol Spectrum Disorder*. SAMSHA Fetal Alcohol Spectrum Disorders Centers for Excellence. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration: April 2004.

⁵ Ibid.

⁶ Birth numbers, too, have risen (from 17,260 statewide in 1988 to 34,347 in Nevada in 2004), though services—including diagnosis—to the FASD population have not changed.

their fetuses to alcohol do so unknowingly (that is, they do not know they're pregnant when they're drinking) or do so without ill intent (that is, they've been told that moderate drinking is acceptable during pregnancy). Given that fifty percent of pregnancies are unplanned; that forty percent of Nevada *teenagers* are four-months pregnant before they realize it; and, that most *adults* are already two-months pregnant before they realize it, it seems that the lifestyles of women of child-bearing age—prior to awareness of their pregnancies—will play some part in determining who puts their child at risk for an FASD. Nevada has the highest per capita consumption of alcohol; seven percent of Nevada women are chronic drinkers; fifty percent of women of child-bearing age drink. These numbers suggest a statewide imperative that we better understand, and implement, effective prevention and intervention strategies.

Individuals and families coping with an FASD often find that in addition to the health consequences of prenatal exposure to alcohol, the behaviors of the individual with an FASD create challenges to normal development and social interactions, academic or vocational progress, and ultimately the ability to live independent from either family or care-takers. Despite the fact that individuals with an FASD generally have a normal intelligence⁷, they struggle with attention deficits and impulse control, judgment, and memory. Although many of the physical and facial characteristics typical of FAS become less prominent after puberty, behavioral and emotional problems become more pronounced, with social maturation seeming to stop at about the level of a six year-old. Studies indicate that fewer than ten percent of individuals with FAS or ARND are able to live and work independently.⁸

The spectrum of disorders represented by FASD ranges from the very mild or moderate to very severe. Diagnosis can be difficult; and finding effective medications, therapies, and knowledgeable care even more so. The range of needs that individuals with an FASD require, from birth through adulthood, may include medical and mental health interventions, Early Intervention and other special education programs, vocational rehabilitation and placement, social services and case management, as well as assisted living of some sort. Many individuals with an FASD depend upon the welfare system as adults; and though no statistics are available, many families and professionals believe that individuals with an FASD are easily coerced into criminal activity and present in large numbers within our prison systems.

Common Behaviors and Characteristics of Persons with FASD

- ✓ *Superficial bonding to family*
- ✓ *Lying and manipulation of family members*
- ✓ *Little Impulse Control*
- ✓ *Difficulty associating behavior with consequences*
- ✓ *Focus on immediate gratification*
- ✓ *Hyperactive in non-goal directed activities*
- ✓ *Need for constant supervision*
- ✓ *Poor social skills with few, if any, long-term friends*
- ✓ *Rage, volatility, and violent outbursts*
- ✓ *Extreme vulnerability to peer pressure, a moral chameleon*
- ✓ *Unable to understand the need for rules and social cooperation*
- ✓ *Childlike innocence despite repeated offenses and consistent consequences*

Source: FASD Centers for Excellence

⁷ Experts suggest that individuals with FAS average an IQ of 79 and that individuals with FAE average an IQ of 90. For more on this, see Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996).

⁸ "Basic Facts About Fetal Alcohol Syndrome and Alcohol Related Neurodevelopmental Disorder" Teresa Kellerman: 1999-2001. <http://fasstar.com>

The consequences of not recognizing an FASD in an individual are significant to both the individual affected, and the systems of care they interact with.⁹ These individuals are frequently very verbal, have a high-IQ, and don't appear to suffer from a disability. Yet, their verbal expressive language is much higher than their receptive language abilities, they have difficulty determining how contextual differences should effect their decision-making and behavior, they cannot "process" multiple instructions, and they struggle to link consequences to their behavior and learn from past experience (and so are not easily motivated by threat of punishment, reward systems, or "natural consequences"). Consequently, individuals with an FASD often fail with traditional education, parenting, mental health- and substance abuse-treatment, and criminal justice approaches. Absent the recognition of a disability, individuals with an FASD are perceived as noncompliant, lazy, and uncooperative.

A large number of children and adolescents with an FASD enter into foster care, adoptive homes, or live with extended family and fail to respond to parenting techniques that adults may have found successful in the past with other children. The learning, disciplinary, and social challenges they experience are typically both frustrating and consuming to their families. Without recognition of an FASD, and without support and proper training on parenting children with an FASD, adults attempting to "parent" these children and adolescents find their homes chaotic, and conclude that the children and adolescents are either willfully "failing" or beyond help. Multiple placements of children with an FASD are very common, and most wind up "on their own" at eighteen without supports or skills they'll need to survive in the community.

And finally, these affected children and adolescents grow up, many to have addictions—and children with an FASD—of their own. They enter the criminal justice system (usually as accomplices, due to their high vulnerability to being manipulated); they enter the welfare system; and they enter the Child Protective Services system. (In Nevada, in 2002, 17.5% of families that CPS found to be abusive or neglectful reported addictions as their primary "stress factor."¹⁰) Without proper "diagnosis" as adults with an FASD, they are perceived as unmotivated, uncooperative, even uncaring and sabotaging when—at the risk of lost benefits, lost custody, or even prison—they are *unable* (without assistance) to complete work plans, court ordered activities, or keep multiple appointments.

The emotional and psychological costs of FASD to the families (often adoptive families) is often devastating; the financial costs to our communities in responding to the myriad needs of individuals with these disabilities is staggering. National attempts to "capture" the cost of FASD to the nation vary between \$75 million and \$4 billion.¹¹

Research attempts at estimating the lifetime-costs for an individual with an FASD have been more consistent. A respected 1980 study estimated \$596,000 per individual (adjusted for changes in health care costs, inflation, and lost productivity this was reported as **\$2 million** in 2002). In 1989, the Alaska State Legislature estimated the lifetime costs of each baby born with FAS at \$1.4 million (adjusted for inflation and rising medical costs, this was reported as **\$2.95 million** per person in

⁹ Dubovsky, Dan. *Fetal Alcohol Spectrum Disorders*. PowerPoint Lecture. SAMHSA FASD Centers for Excellence. Las Vegas and Reno, NV: January 2006.

¹⁰ Nevada Division of Child and Family Services, Family Programs Office. *Child Abuse & Neglect Statistics: 2002*. <http://www.dcfs.state.nv.us/Reports/2002%20Statistics-Final.pdf>

¹¹ The substantial difference in estimates reflects assumptions about the actual birth-rate of children with an FASD, differences in medical and residential services researchers assumed they might access in their lifetime, whether researchers estimated costs for individuals from birth to 21, or birth to 65, and inflation between the years in which different studies were conducted.

2002) though that number is universally understood to be conservative as it doesn't include medical services for some common physical anomalies, welfare payments to the families, mental health services, criminal justice costs, services for mild physical problems and learning disabilities, or lost productivity of caregivers and persons with an FASD.¹²

No such studies or attempts to "capture" the "costs of FASDs" have been conducted in Nevada.¹³ However, experts from the *Centers for Excellence on Fetal Alcohol Spectrum Disorder* most frequently use the 2003 work from the Lewin Group which estimates the lifetime health costs for individuals born with FAS at \$860,000, and the reduced lifetime productivity, lost wages, and subsidies at an additional \$200 thousand. These experts argue "even 'expensive' FAS prevention may be cost effective up to \$850,000 per child."¹⁴

Most recent prevention efforts in Nevada have included NRS 446.842 and a Public Awareness campaign coordinated by the Bureau of Family Health Services' Perinatal Substance Abuse Prevention Subcommittee. The statute requires that signs be posted in any food establishment in which alcoholic beverages are sold by the drink, for consumption on the premises. The public awareness campaign targets pregnant women and is designed to educate them about the dangers of fetal alcohol syndromes and other adverse effects on a fetus that may result from the consumption of alcohol during pregnancy. To date, Nevada has no mechanisms in place to measure the frequency of children born with an FASD, nor the impact of recent prevention activities.

To paraphrase a Nevada parent, speaking on behalf of her adoptive son, Fetal Alcohol Spectrum Disorders have gone undiagnosed, but not unpunished, for too long. Individuals and families affected by an FASD have been isolated without support and appropriate services; our communities have suffered for our lack of research, and preventative activities. As this report will go on to demonstrate, there are few public leaders, public systems, or community services that don't have a role to play in supporting thoughtful, responsive prevention and intervention initiatives.

¹² Lupton, Chuck. *The Financial Impact of Fetal Alcohol Syndrome*. SAMSHA Fetal Alcohol Spectrum Disorders Centers for Excellence. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration: 2003.

¹³ An FAS Prevalence and Cost Calculator can be downloaded from the Online Clinic, a project of the *Fetal Alcohol Syndrome Center* at the University of North Dakota: <http://www.online-clinic.com/content/index/index.asp>

¹⁴ Harwood, Henrick. "Economic Costs of Fetal Alcohol Syndrome." The Lewin Group: Fairfax, VA 2003.

NEVADA'S TOWN HALL MEETINGS

Recruitment and Coordination

The Perinatal Substance Abuse Prevention Subcommittee (PSAP) of the Maternal and Child Health Advisory Board convened two Town Hall Meetings in Nevada, one in Las Vegas on January 17, 2006, and the other in Reno on January 23, 2006. Meetings were coordinated and facilitated with assistance from Nevada's Bureau of Family Health Services staff and a private contractor.

The Subcommittee designed community-specific promotional flyers (See Appendix A), which were mailed to 253 individuals and organizations in southern Nevada and 286 in northern Nevada to solicit participation in these events. These individuals and organizations included physicians, social workers, legislators, and parents, as well as representatives from school systems, Family Resources Centers, Head Start centers, drug courts, tribal organizations, and community coalitions. Personal letters and promotional materials were also sent to a variety of organizations whose services might extend to families affected by an FASD. Finally, PSAP Subcommittee members created a list of their own personal and professional contacts who should be encouraged to attend and provide testimony; each of these individuals was invited personally by the private contractor.

RSVPs were solicited prior to the meetings, and individuals were encouraged to prepare and submit their testimony in writing (to both keep oral testimony focused and within the 10-minute time-limit, and to increase the accuracy of report-writing following public testimony). However, all promotional materials, and all conversations prior to formal testimony, encouraged individuals to provide testimony whether they had provided an RSVP to the meeting or not.

Simultaneously with promotion efforts within Nevada's communities for public participation, the PSAP Subcommittee invited a number of State leaders to participate in Town Hall Meetings as panelists. Invited personally by PSAP Co-Chair, State Senator Maggie Carlton, they were selected according to their ability to listen carefully and ask critical questions (given their informed professional background), and to bring perspective and influence to any legislative or policy-level activities initiated by what we learned during the Town Hall Meetings. (See Acknowledgments for a list of panelists).

Town Hall Meetings were hosted at sites chosen for their accessibility to the public: the Las Vegas meeting was held at a Family Resource Center, and the Reno meeting was held at a Washoe County Library. Refreshments were available at meetings, and PSAP Subcommittee members, Bureau of Family Health Services staff, the meeting facilitator, and the guest speaker from the national FASD Centers for Excellence attempted to speak with all in attendance to encourage public testimony and commitment to this issue.

The Town Hall Meetings were attended by seventy-eight participants; eighteen provided testimony. Participants included:

- ✓ Seven parents (all either foster- or adoptive parents), and one adolescent with an FASD
- ✓ Twenty-one health care professionals
- ✓ Eleven social workers
- ✓ One representative from a Nevada School District
- ✓ Three state leaders from the Senate and/or judiciary

State agencies and organizations represented include: Bureau of Family Health Services, Court Appointed Special Advocates, Friends of Special Children, Washoe County Social Services, Division of Mental Health and Developmental Services, University of Nevada, School of Medicine, Washoe County District Health Department, Nevada State Welfare Division, Clark County School District, Nevada Early Intervention, Division of Child and Family Services, and the Nevada State Senate.

Meeting Procedures and Data Analysis

Each meeting began with PowerPoint Lecture from Mr. Dan Dubovsky, of the SAMSHA Fetal Alcohol Spectrum Disorders Centers for Excellence. Lectures emphasized the emerging research and community-organizing around FASD, and the significance of this work to individuals with an FASD, their families, and the communities that struggle to integrate and care for them. In addition, his lecture provided context for testimony, as he discussed the neurological and behavioral disabilities (and consequences) commonly seen in children, adolescents, and adults with an FASD (His slides can be seen in Appendix B).

Prior to entertaining public testimony, panelists were asked to introduce themselves and briefly discuss their professional “intersection” with FASD; the overwhelming majority of panelists expressed sympathy and commitment to using their own professional influence toward the enhancement of prevention and intervention initiatives, policies, and/or services.

Persons providing testimony were asked to submit testimony in writing; those who did not or could not were asked to review this report in draft to insure that no information or experiences were misrepresented. Detailed notes were kept during each person’s verbal testimony; no one spoke for more than 10 minutes. Everyone who intended to provide testimony was given an opportunity to do so.

Notes and submitted testimony were then reviewed and organized, into large categories of comments: 1) Concerns/issues raised regarding adolescents and adults with an FASD, 2) Concerns/issues raised regarding young children with an FASD, 3) System’s Responses to Persons with an FASD, and 4) Suggestions (from testimony) for Programs and Services. Within those categories, comments were then “grouped” and notes created about the number of individuals who emphasized the same issues or needs (See Appendix C).

Any issues, common experiences, or suggestions for services that were mentioned by more than five individuals were used to create the “Defining Issues” section of this report, and will be the issues most directly addressed by our recommendations.

R e s u l t s

The majority of testimony was provided by adoptive or foster parents, followed by strong representation from social service providers working with individuals with an FASD within their communities. The most frequently-mentioned issues effecting individuals, families, and service providers were:

- ✓ allied professionals lack education, sympathy, and effective involvement;
- ✓ the isolation felt by individuals with an FASD, and that felt by their families;
- ✓ the challenges and delays almost universally experienced in accessing a “diagnosis,” and the scarcity of appropriate services and resources for individuals with an FASD;
- ✓ the unmitigated burden born by Foster- and Adoptive-Parents in caring for children with prenatal exposure to alcohol; and
- ✓ the lack of appropriate supportive and transitional services for adolescents and adults with and FASD.

Interestingly, although there was some emphasis from a few professionals on the importance of intervention with birth-mothers of affected children as a form of prevention, *prevention activities were seldom mentioned*. As in many social change movements with similar tensions between prevention and intervention (substance abuse, child abuse, domestic violence), there will certainly be debate about how many resources should be committed to prevention when families currently suffering with the effects of an FASD have very few services and supports. However, we feel this report would be remiss if it did not discuss preventative activities within its recommendations.

DEFINING ISSUES

While personal and professional experiences were varied, and expressions of needed services and most challenging barriers equally diverse, testimony from Nevadans fell quite consistently into the “categories of concern” mentioned on the previous page. Each “Defining Issues” is addressed in turn below.

Lack of education, and consequently lack of sympathy and effective involvement of allied professionals (courts, teachers, health care providers, mental health professionals).

Parents participating in Town Hall Meetings spoke with almost universal frustration about their attempts to secure informed and effective support for their children with an FASD. Their most common frustrations were with the health care community and Nevada school systems—the systems they depend upon most for their own education about their children’s disabilities. Their frustrations fell into two categories: 1) finding professionals who accurately recognized and understood FASD as a disability; and 2) finding professionals within the medical community and school systems who had adequate training and sympathy to be responsive to the range of needs an individual with an FASD presents.

Lacking physical characteristics of FAS, and often having a normal IQ, children and adolescents with an FASD function with a “hidden disability,” unless trained professionals recognize the behaviors and challenges typical of this disability, and respond appropriately.

Hoping to learn from professionals within these systems about the impact of FASD (attending mental and physical challenges, behavior modification, resources, promising interventions, etc.) parents often found themselves forced into the role of expert. One parent commented that, ““Every time we encounter a new physician, psychologist, psychiatrist, or counselor, I find I must educate *them* about FASD.” Indeed, we heard repeatedly that even if parents were able to determine early in their child’s life that s/he suffered with challenges associated with prenatal exposure to alcohol, the diagnosis was not particularly useful if they could not then proceed to access services from knowledgeable physicians, mental health professionals, and teachers.

Parents of infants and toddlers often are directed toward Nevada Early Intervention Services (NEIS) where Early Intervention staff (administered by the Nevada State Health Division, Bureau of Early Intervention Services) creates an Individual Family Service Plan (IFSP) which considers the family’s strengths, goals, resources, and environs. None of the parents providing testimony mentioned the IFSP. Several, however, mentioned the subsequent development of the Individual Education Plans (IEPs) which are developed by the school district. Parents commonly found that because the FASD is inconsistently recognized as the primary developmental disability, the IEP is not effective (children with an FASD are commonly diagnosed with more recognizable challenges like Attention Deficit Hyperactive Disorder, Autism, Attachment Disorder, Oppositional Defiant Disorder, and Anxiety Disorder, all of which are secondary to the FAS diagnosis). The same problems are reported among

“He tests well, has a high IQ, and gets no services. He knows he’s different, and with two to four extra hours of homework he’s still failing the 1st grade.”

parents whose children received 504 plans.¹⁵ Commonly, parents find that the accommodations recommended by these plans aren't available, or that teachers have neither resources nor training to honor them. And, children with an FASD are erroneously medicated over years of attempts at behavior modification.

Emotional responses of the adoptive parents we heard from to “the school district’s” management of their children’s educational plans ranged greatly: One parent of a younger child commented, sympathetically, that “His teachers wanted to help, but didn’t know how.” Parents of an adult with an FAS diagnosis depicted their role as advocates: “All educational services for these children were directed by the school system, and it required constant parental intervention and modification to meet their needs. . . Working with the school systems in Arizona and Nevada was a most difficult and exhausting task. Almost always, services fell short of the recommended IEP.” And one parent (also an employee of Clark County School District, where her daughter attended) was angry and antagonistic: “From my experience the Clark County School District has been the biggest barrier to my daughter receiving services. . . From the beginning when I started asking for help, testing, and services. . . there has been systemic and institutionalized stone-walling, deception, refusal, lack of cooperation, and outright lying and deliberate dishonesty.”

The *social* challenges encountered by children with an FASD within the school systems fit into recognizable patterns; throughout the course of our Town Hall Meetings parents providing testimony would describe the ways in which their children were outcast or punished to the understanding—often adamant—nods of other parents in the room. Behaviors and characteristics typical of persons with an FASD include having little impulse control, difficulty associating behavior with consequences, poor social skills and seeming inability to read “social cues,” rage and volatile outbursts, and an inability to understand rules and the need for social cooperation. In addition, children with an FASD typically cannot anticipate consequences of their behaviors; reward systems must be immediate and concrete (as opposed to conceptual). So, earned privileges and/or the potential for punishments (within classrooms or criminal justice systems) aren’t meaningful methods for behavior modification. Children with an FASD are frequently outcast and isolated from their “normally-functioning” peers, and the structure and discipline of the typical Nevada classroom doesn’t allow for these behaviors to go unpunished, or to be anticipated and appropriately refocused.

Finally, parents described the difficulties they faced when these learning disabilities and behavioral problems resulted in “interventions” from teachers, counselors, mental health practitioners, etc. Because FASD often causes Central Auditory Processing Disorder, oral communication—which is predominant in school, social service, and therapeutic systems—isn’t “organized” or processed normally, despite the child’s apparent understanding and compliance at the moment. When interventions don’t result in behavior changes, the child is often stigmatized by unknowing adults as uncooperative or defiant.

¹⁵ Section 504 is a civil rights law that prohibits discrimination on the basis of disability. Under Section 504, students can get the accommodations and services they need to be with other students who do not have disabilities in their classroom and school activities.

In addition to the challenges posed by finding appropriate interventions, parents and school districts are faced with a real conundrum about how and where to “place” children with an FASD. In some Nevada school districts, parents asking that their child’s disability be recognized as such so that they can place their child in Special Education classroom find that FASD is not a recognized disability and are denied special education services. In other districts, any diagnosis within the spectrum is sufficient for services.

“Most of my teachers did not want to learn about FASD, not even the Special Education people. People look at me and think I am not affected by FAS. They think I’m cute, smart, and only 12 years old. I’m 19. I’m afraid you won’t believe me, because nobody at school would.”

Parents often desire placement of their child in a classroom setting which is more responsive to their individualized needs (as well as their need for a classroom in which they are not ostracized by peers). If they are awaiting diagnosis, or are in a district that does not recognize FASD as a disability, many feel pressured to accept a secondary (and less accurate) diagnosis; one mother commented on her son’s diagnosis as “Severely Emotionally Disturbed” as an “unfair label—he’ll get services, and that’s good, but I think he’s extremely emotionally healthy considering what he’s been through, and the disability he functions with. . . and my goodness, what a label to have on you.” However, parents suggest that Nevada Special Education teachers have no more training on FASD and it’s attending behaviors than teachers of traditional students, and experts have suggested that mainstreaming children with an FASD may be more helpful to them so that “normal” social interactions are consistently modeled for them. As one mother argued, “Teachers must be educated in the disabilities they are encountering . . . Administrators must be educated in the disabilities they are passing judgments on.”

Finally, while the majority of “systemic educational” concerns seemed focused on health care and school systems, parents and professionals alike mentioned their concerns about these children as they age out of the school systems. The same cognitive and behavioral challenges that cause children with an FASD problems in school, cause adolescents and adults problems with law enforcement, and the same models of intervention—step systems, anticipating consequences, receiving information in ineffective settings which require auditory processing—result in similar failures and conclusions that the individual is uncooperative, rather than unable to modify their behaviors. One mother implored the group to “please stop using the criminal justice system to cure brain injury;” similarly, an FASD Intervention Specialist asked us to consider “whether it is ethical to put a person with a cognitive disability in prison?”

BARRIERS

- Medical Community’s training limitations in identifying FASD, and recommending appropriate medical and behavioral interventions
- School System’s training limitations in identifying FASD, and developing appropriate responses to the learning needs of children with an FASD
- Criminal Justice and Law Enforcement’s training limitations in responding to adults with an FASD, and systemic question about “what to do” with adults who don’t “belong” in this system
- Fetal Alcohol Spectrum Disorder is not considered a “disability” and so services are not automatic, and systemic responses and supports not developed

OUTREACH PRIORITIES

- **Health Care:** Strategic planning around identification, treatment, referrals within medical and nursing schools, and schools of social work, and organizations providing continuing education
- **School Districts and Bureau of Early Intervention Services:** Strategic planning around introducing curricula and continuing education opportunities for Colleges of Education, Special Education teachers and administrators, Early Intervention programs, and School Administrators about FASD, treatment, and Best Practices. Simultaneous efforts to work with School Districts and Bureau to create disability status for children with an FASD
- **Criminal Justice:** Work with judges, P.O.S.T. (Peace Officers Standard Training), Medical/Mental Health professionals within prisons and jails to better understand alternate sentencing options for adults with disabilities; investigate the possibility of providing training and advocacy within the criminal justice system.

Isolation of families of children with an FASD

Interestingly, at no point during Town Hall Meetings did a single parent or allied professional refer to any service or advocacy organization, book, or online resource which had assisted them in accessing helpful resources, or networking with other parents of children with an FASD. Some spoke of the support they received from Early Intervention offices (though that support seemed to be focused, reasonably enough, on services available through the school districts); and some spoke of their gratefulness in learning of Dr. Colleen Morris, the only physician in Nevada who offers FASD diagnoses to individuals over the age of three (though Dr. Morris, herself, spoke of her frustration in offering a diagnosis, and having no support centers or services to then recommend). However, it became quickly evident that parents of children with an FASD are isolated in their experience, without the insight of other parents with similar experiences, without resources and support services, and without a central “repository” of expertise, referrals, system’s advocacy, or education on the disability. Parents of older children with an FASD spoke of their long searches for appropriate services and helpful resources; parents of young children with an FASD spoke of “beginning their search.”

“Lost days at our jobs, lost income, lack of respite care services and the cost of all the uncovered services have exhausted our resources. My husband and I are beyond our capabilities as parents to help him with mental health needs. We are beyond our expertise level to help him with the life skills he simply does not demonstrate. As parents, we have moved nearly as far as we can—and we now need help.”

Parents frequently expressed the need for a safety net, someone or some place to call when they’re overwhelmed and need immediate help. Clearly, some parents conceived of this “safety net” as a kind of hotline, staffed by knowledgeable people who could provide insight, referrals, and “strategies” for receiving service, or modifying their children’s behavior. Other parents mentioned a “safety net” with the intention of respite care—a center or network of safe and knowledgeable homes, where their children could safely stay while parent, siblings, etc. could regroup.

The need for “respite” is driven not only by the “round-the-clock” supervision that children with an FASD require, and the challenging nature of that care, but also by three significant stressors almost universally experienced by parents of children with an FASD: 1) the consistency and frequency with which parents are required at medical appointments, IEP meetings, and pre-school and school settings to mediate or respond as their children are punished for unacceptable behaviors; and, 2) the paucity of day-care and after-school programs prepared and willing to watch children with an FASD; and, 3) the haunting worry several parents articulated about “what will happen when I’m gone?” Few families of children with an FASD can have both parents work full-time—even while the child is of school-age—and many are preoccupied with their inability to simultaneously attend to the immediate needs of their child and work with sufficient longevity and professionalism to establish retirements, savings, etc. adequate to care for themselves and their dependent children well into their child’s adulthood. Single parents face an even more challenging financial- and time-management burdens, and feel even more isolated in their struggle. Again, the degrees of frustration among parents varied, but the need was the same. One father commented that, “Once Matthew started elementary school, the real fun began. . . he never got into any real trouble, but I had to quit my job since I was either sitting next to him in class or in the principle’s office daily.” Another mother described her crisis of care: “Finally, by the time he had reached the 8th grade, Daniel¹⁶ had become so unmanageable that I was unable to care for him. I approached the state and after extensive searching, we found a local group home, where Daniel lasted about one month . . . the group home had also had a difficult time, and gave up on him. Daniel was taken to a local psychiatric hospital where he spent 9 months.”

“I dedicated my life to this child without the proper help from any agency, state, local, or private. All the while I got, ‘What’s FAS?’”

The same stressors effect families providing foster care of children with an FASD. We repeatedly heard of foster parents who had provided care to many children over many years, and whose homes and parenting strategies had been healthy and effective until their first child with an FASD. Some of these parents do choose to adopt the children, however one parent shared that the behavior of her foster-son became so out-of-control that “the state” worried he was a danger to the other children in our home. “Michael was removed and put into an institutional setting.” She wondered aloud what might have been possible for him if some appropriate programs had existed.

In addition to identifying a desperate need for respite services, and safe, informed day- and after-school care, parents also identified the need for intervention-oriented services and support. Parents requested a mechanism for learning and networking, for attending parenting classes and workshops that are taught by experts who won’t “emphasize futile parenting techniques for children with this disability.” These suggestions for “support services” extended to the education of therapists and mental health professionals, and the development of a “list” of therapists who could provide appropriate help. Currently, parents looking toward therapy models are met by professionals who use cognitive therapy models (which haven’t proven effective with individuals with an FASD). One adoption social worker commented that, in nine years in her profession, she’s only met one therapist who appropriately shifted from cognitive therapy models to parenting-techniques and “environmental adaptations.”

Finally, parents suggested that every time they encountered a new “system” they were forced to educate professionals about this disability. Many felt overwhelmed by the repetitive task; many felt that they were perceived as over-protective or hyper-vigilant, and many felt that they didn’t know enough about a given system (usually school system or criminal justice system) to effectively advocate

¹⁶ Names of the children and adolescents mentioned in public testimony have been changed in this report for their confidentiality.

for their children. Parents suggested the development of an advocacy system, where informed professionals could work with families, schools, courts, etc. to educate, suggest “what is needed” and even to assist the individuals with this disability.

BARRIERS

- No existing central “repository” of Nevada-specific information, referrals, resources, or mechanisms for parents (and professionals) to network and receive training specific to this disability
- Availability of safe, knowledgeable respite care for children and adolescents with an FASD
- Availability of advocates to provide systems’ advocacy and education

OUTREACH PRIORITIES

- **Special-Needs Parenting Coalitions:** Find and allocate seed-money, grants and administrative technical assistance, strategic planning and “model programs” for establishing an advocacy and education center.
- **Child Care Providers:** Contact the State Child Care Development Block Grant administrators, Children’s Cabinet, Nevada Head Start programs, and private providers to provide education and training; suggest creation and funding of FASD pilot program child care sites (provide training and technical assistance).

Infrequency and unavailability of accurate diagnoses,
and the related scarcity of education and intervention
services

Parents and professionals alike testified to the need for significant attention to and development of Nevada’s capacity for diagnosis of FASD, and for the provision of services which are responsive, and specific to FASD.

Currently, families with children over the age of three years-old can receive a genetic and behavioral assessment from only *one* Nevada physician, Dr. Colleen Morris, who works with the University of Nevada School of Medicine (UNSOM) in Las Vegas, Nevada. In a familiar aside, one mother noted that she had, “[W]aited two years for diagnosis, and *I* was able to be a strong advocate for my son.” The absence of a professional assessment and diagnostic “community” has had multiple discouraging effects on the families and systems coping with FASDs.

“I was beside myself, researching and looking for help in any way I could. . . . Getting information and help from national experts for Daniel’s serious terminal medical condition became much easier than getting . . . to the root of his emotional and cognitive problems. This was a long, tedious, and exhausting process.”

First, parents and professionals spoke of the exorbitant amount of time, money, and energy committed to children affected by FASD that didn't directly address their disabilities. Commonly, children with an FASD are misdiagnosed or unknowingly diagnosed with only co-occurring disorders. And so, services are often designed around secondary diagnoses (Autism, ADHD, Oppositional Compliance Disorder, Anxiety Disorders, Bipolar Disorder, etc.) One mother described her experience trying to get an effective diagnosis and educational plan for her son like this: "He was diagnosed as ADHD on my insistence for testing, and the challenges with schools, teachers, special education facilitators and teachers of record throughout his education is documented in a file at our home that staggers the imagination. Not one, two, but often three or more meetings were requested every year to modify his IEP for specific needs. All the teachers couldn't understand how a bright, normal IQ individual could have so much trouble with homework and grades."

Second, the absence of a diagnostic community has essentially "silenced" the disability from more typical prevention and intervention rubrics. The handful of treatment professionals in attendance at these meetings emphasized the need for research (funding), and the need to tie outcomes to that research; social service professionals commented on the limited scope of prevention efforts in Nevada; treatment professionals, social service professionals, and parent all implored us to deem FASD a disability so that individuals affected by an FASD would be eligible for services and support. A representative of Nevada's Division of Child and Family Services Adoption Services commented that, "We need it to provide services, we need it for removals and placements. Without diagnosis, they're precluded from services and precluded from support from SSI, from school districts, and from post-adoptive services."

Finally, we can reasonably assume that the scarcity of appropriate diagnoses has allowed the comparable scarcity of services; neither of these are proactive or accurate reflections of Nevada's needs. (National statistics suggest that FASD occurs in 10 per 1,000 births. Nevada statistics suggest a similar rate, approximately ten times the occurrence of Down Syndrome).¹⁷ A CASA (Court Appointed Special Advocate) professional noted that ". . . we have not seen specialized diagnosis for FASD of children in northern Nevada. There may be presumptive diagnosis but this usually comes late with respect to the need, and only after considerable effort. *We need specialized diagnosis and case management in every community.*"

"It took me 9 months to see a genetic specialist for diagnosis, and this was after my son was in psychiatric residential treatment for a year."

He goes on to describe his experience with Nevada courts and mandated services: "There are a variety of mandated referrals to services for children affected by prenatal drug and alcohol use. But there is not tracking of services delivered and no adequate hand-off from one agency to the next or from childhood to adulthood. *We need to make community based, team focused, seamless diagnosis and case management to children and adults the goal. And we need to actually do it, not just talk about it* (emphasis his)."

Currently, there are no existing programs in Nevada designed to respond specifically to the needs of children (or adolescents and adults) with an FASD. Treatment professionals commented that, "We need a dedicated clinic where parents can seek diagnosis, and pursue parenting plans and support services." Professionals who worked more frequently with special-needs advocacy communities specified that, "We need a place where there are professionally developed materials for parents to

¹⁷ May, P.A., and Gossage, J.P. 2001. Estimating the Prevalence of fetal alcohol syndrome: A summary. *Alcohol Research & Health*, 25(3): 159-167.

help them with strategies, managing behaviors, and anticipating next stages, next challenges or resources.”

Though most discussion about diagnosis and subsequent interventions focused on the significance of early diagnosis and early intervention, several professionals in attendance had ethical and monetary concerns about the significance of diagnosis and treatment for adolescents and adults with an FASD. Many adults with an FASD repeatedly enter the welfare systems, and criminal justice system, with limited ability to learn from past experience, complete self-sufficiency plans, perform court-ordered activities, etc. One treatment professional asked, “If someone’s brain is broken; and the system isn’t working for them, which can change?” Many argued that the solution, for an adult population, was what some called “seamless diagnosis and case management,” others referred to it as a multidisciplinary approach, “involving medical, mental health, educators, teachers, and community support circles.”

BARRIERS

- Scarcity of professional medical geneticists to provide accurate assessment and diagnosis for children over the age of three.
- Absence of a diagnostic “community” has allowed absence of research, prevention activities, and FASD-specific services and interventions in Nevada. There is no “center” of knowledge or services from which knowledge or support can be initiated.

OUTREACH PRIORITIES

- **University of Nevada School of Medicine:** find funding and create pressure/motivation for UNSOM to 1) create fellowships for geneticists, pediatricians, and child- and adolescent-psychologists to do rotations with Special Needs children; and 2) hire and support the community work (diagnostic assessment) and research of geneticists.
- **Legislature:** Fund and organize a Pilot Project, with Outcome Measures, which creates a “center” for FASD Family Services, including assessment and diagnosis, prevention campaigns, referrals and family parenting plans, and training and technical assistance to para-professionals.

Burden born by foster and adoptive parents

The needs of children with an FASD were largely represented by their adoptive parents, though a few foster parents did attend Town Hall Meetings and provided testimony (at neither Town Hall Meeting did we hear from any birth-parents of children prenatally exposed to alcohol). Though none of the parents offering testimony expressed regret about adopting their children or even about the adoption process, one pattern became remarkably clear: few adoptive parents know, prior to adoption, the health history of the children they’ll parent.

Most parents spoke of this missing information only in providing context for the challenges they themselves faced in identifying and diagnosing FASD. One mother described her hope, and the state adoption case manager's ignorance with a chuckle: "The state case manager stated that the children had normal IQs and seemed to be relatively "clean" of the types of problems seen in most children they have in their system. They were cute, irresistible, blond-haired, blue-eyed brother and sister focused on having a 'forever Mommy and Daddy'." Another mother described her devastation: "After Natasha had been with me for three years, I knew something was not right developmentally and emotionally and set about trying to find out what. . . The day I received the diagnosis of an FASD I broke down and cried as my research had taught me exactly what that meant for my daughter." A third adoptive mother's frustration seemed to be directed solely at her son's birth-mother:

I have raised him alone since he was two years-old. At that time, I had virtually no information about Daniel's birthmother, but later found out that she had used alcohol extensively while she was pregnant. At no fault of his own, Daniel was prenatally exposed to alcohol and will pay the price for his entire lifetime. His neurological damage went undiagnosed for a long time, but not unpunished.

Nevada Revised Statute¹⁸ requires that adopting parents be provided with a report which includes medical records and other information concerning the child, including any medical records of the child (which are in the possession of the agency which provides child welfare services or licensed child-placement); any information obtained by those agencies regarding the medical and sociological history of the child and the natural parents of the child; and, any behavioral, emotional or psychological problems that the child may have. However, no statutes or policies currently exist which require child welfare services or licensed child-placement agencies to *investigate* the likelihood of prenatal exposure to alcohol or behavior consistent with an FASD.

Many parents mentioned the inequities between the supports available to foster- and adoption-families. Nevada Revised Statute¹⁹ does make provisions for providing financial assistance to families adopting children with special needs. By law, the agency which provides child welfare services or licensed child-placement is required to schedule any evaluations necessary to identify any special needs the child may have. Upon determining that the child has special needs, the agency is to notify the proposed adoptive parents that they may be eligible for financial assistance and assist the proposed adoptive parents in applying for and satisfying any other prerequisites necessary to obtain a grant of financial assistance. However, the grant of financial assistance must be limited, both in amount and duration. And, all financial assistance provided under this section ceases immediately when the child attains majority, becomes self-supporting, is emancipated or dies, whichever occurs first.

"Once I adopted my son, most supports disappeared. When he turned 18, they disappeared entirely, at the same time that our insurance stopped covering him."

Even so, children with an FASD are not consistently considered "Special Needs," and so adoptive parents are eligible for none of this support. An adoption social worker testifying at the Reno Town Hall Meeting spoke of how discouraging her work often was, knowing that the foster parents she works with will lose so many support services upon successful adoption, and that there are so few resources for children with this disability.

¹⁸ [NRS 127.152](#)

¹⁹ NRS 127.186

An adoptive parent spoke of the overwhelming needs her adoptive children presented (medical, psychological, and educational, as well as physical-, occupational-, and speech-therapies), emphasizing that these needs lasted long beyond her children’s “transition” from foster care to her home: “When the adoption became final. . . [they] provided an adoption case manager, a small monthly maintenance fee, medical assistance for specifically designated needs such as psychological counseling and respite care. Medical financial services were provided only for fees beyond what our insurance provider would cover. All other services went away.”

BARRIERS

- No requirement that child welfare agencies and licensed child-placement agencies investigate the likelihood that the children they’re placing have been prenatally exposed to alcohol
- Inequities in financial and other supports between foster families and adoptive families
- FASD not qualified as “Special Needs” for financial aid purposes for adoptive families

OUTREACH PRIORITIES

- **Legislature:** Deem FASD suitable to Special Needs status within Child Welfare agencies, and consider passing amended statutes requiring child welfare agencies and other licensed child placement agencies to investigate the likelihood of prenatal exposure to alcohol and other drugs.
- **Medicaid:** Investigate the possibility of lifetime health benefits for adopted children with Special Needs; give children, adolescents, and adults with an FASD disability-status.

Lack of appropriate supportive or transitional services for adolescents and adults with an FASD.

Parents of adolescents and adults with an FASD spoke during our Town Hall Meetings of the transition from frustrations within school systems which did not adequately respond to their children’s disabilities to new frustrations and worries about the future of their children who “seemed to fit nowhere but in the cracks.”

Challenges that parents of younger children with an FASD met in finding child care becomes even greater when, as one parent described it, her “seemingly normal,” high-IQ kid aged out of day care systems but needed constant supervision.” After-school programs for adolescents, transitional programs for special needs populations, and residential programs were described repeatedly by parents as unprepared for these individuals. Said one father, “With no help and no programs available in Nevada, things started getting bad . . . We found a private program in Utah. Expensive! It was short of a lockdown facility. Once again they said, ‘What’s FAS?’ He lasted nine months before they begged us to come and get him.”

“Eventually my son would like to live independently, but he will need help. He is unable to drive but thinks he can. He will need constant supervision because of his poor decision-making abilities, yet he hates being prompted.”

Though they were concerned about the availability of assistance with “supervision” of their FASD children, most parents of adolescents and adults with an FASD were primarily concerned with the

safety and dependence issues that arose for them. Speaking of her son who was approaching the end of high school, one mother said that “Daniel most needs transition services—to insure that he starts training for a job NOW rather than waiting until he’s eighteen. I hope and pray that I can see him graduate, and that he continues to stay out of the justice system, or become prey to abusers and predators. I have kept Daniel basically on the right track until now, but now I’m asking for help. Please don’t let him fall through the cracks.”

Another mother, whose son had recently completed high school, spoke of that transition: “The school system provided job-related training; but, because he had passed proficiencies and did not plan to attend college, there were no other services the school could or would provide . . .” She went on to describe the services they *did* pursue:

Through Vocational Rehabilitation we contacted ASAP (Accessing Services and Programs), a non-profit funded by the state of Nevada. This group has been working with Voc Rehab on services for my son. They provided a job coach and an advocate that attended our application with Social Security. They provided valuable information on services. We also know that, at some point, these temporary 90-day services would end. What happens when my son gets to his 10th unsuccessful job placement?

Most parents were unanimous in their belief that the “answer” to both supervision-needs and life-skills development would be in the creation of community campuses to provide training and skill development. Parents went on to specify that the “campus” might offer job skills training, money management, daily care issues, medication issues, emotional monitoring, as well as workshops and therapy for adolescents and young adults with an FASD, providing them skills for anger management and survival despite their given limitations.

Parents and professionals in attendance described, too, some of the barriers for their children in accessing *existing services* (designed for lower function, special needs populations) which may be helpful. As one mother put it, “If my son had more problems we’d get more help.”

Because most individuals with an FASD do not have autism, and frequently have an IQ higher than 60, assisted living programs through social services can’t help. Yet, their parents and social service providers argue, these individuals cannot live independently. A northern Nevada social service provider was emphatic about the need for more appropriate service thresholds for adults with an FASD: “Change the standard for receiving case management. Current eligibility standards are outdated. Cognitive ability above 72 means no supportive services through the state.”

We need to “Provide a system of advocates who can help manage the financial and other affairs for those with FASD so they do not become homeless.”

Parents clarified, too, that by lacking a recognized “disability diagnosis” their children find themselves at risk with no support services. One mother reported that, “We have been told time and time again that without social security approval, services for my son were nearly non-existent.” Professionals attending our Town Hall Meetings suggested that in the absence of appropriate transitional and residential services and case-management in our communities we see, and will continue to see large numbers of adults with an FASD in our welfare and criminal justice systems.

The Nevada State Welfare Division currently holds a contract with a Nevada expert in FASD who helps with assessments and work plans for adults with this “barrier to self-sufficiency.” Though this contract, and the resulting work plans have been helpful, several social workers provided testimony describing the challenges that adults with an FASD have in functioning independently and in succeeding within the welfare system.

Many social workers described the number and complexity of tasks adults need to complete to maintain support and meet eligibility, and suggested that even if adults with an FASD worked with a social worker (rather than eligibility and employment workers), the welfare system simply could not provide them with the intensive case management they require to succeed. Social workers described case plans which involved resolving medical, mental health, and criminal justice issues; substance abuse and addiction; open CPS case plans, vocational training and preparation; housing, transportation, and child care. Overwhelming tasks for adults without a cognitive disability, adults with an FASD struggle to prioritize, organize, or communicate clearly about these and other needs. Perhaps even more frustrating to welfare social workers was knowing that as soon as their support was withdrawn (usually because of mandatory sit-out and federal lifetime time-limits on TANF receipt), individuals with an FASD would typically “lose any ground” they gained with welfare’s support. As one experienced social worker expressed it, “How well would you survive if you had to ride the bus everywhere, but could only remember the last direction you were given?”

Southern Nevada social workers had placed some hope in their experience with an eighteen-bed Residential Substance Abuse Treatment facility in Clark County into which they occasionally transitioned FASD adults. Last year, of five cases of recognized FASD, two individuals stayed for 18 months, receiving intensive case-management and assistance, and “successfully” transitioned to their family’s homes. Two individuals went into the prison system, and one individual is no longer in contact (they fear she is homeless or dead).

Adoptive parents, concerned for the safety of their children who often fall prey to predators and peer pressure, well-understood the possibility of their children ending up in the prison system. Some suggested an addendum to their identification identifying FASD (and their limited ability to understand Miranda rights, etc.). Others asked that the court system consider requiring immediate screening for FASD before legal proceedings if reason exists to suspect the disability. Treatment professionals in attendance emphasized that, while many adults with an FASD *were* in our prison system, that prison would neither keep them safe nor act to deter them from unlawful behavior in the future.

The Department of Corrections’ Southern Nevada Women’s Facility was represented at the Town Hall Meeting held in Las Vegas by the Associate Warden, as well as the nurse who provides on-site prenatal education to incarcerated women. Neither woman questioned that a large population of inmates suffered with an FASD, and in fact spoke of the multi-generational existence of the disability. The nurse providing testimony spoke of the ignorance many women had of their own bodies—birth control, pregnancy, and delivery—and of their incredible desire to learn. She asked that we begin prioritizing education for this high-risk population as both a step toward enhanced intervention *and* prevention.

BARRIERS

- Existing transitional and residential programs for adolescents and adults are unprepared for the needs and behaviors common to adolescents and adults with an FASD
- No availability of transitional services—life skills classes and vocational training—for adolescents and adults with the challenges specific to FASD
- Adolescents and adults with an FASD cannot access existing transitional and independent-living services because they are not autistic, because their cognitive functioning is frequently higher than 60, and because FASD is not a recognized disability
- Nevada State Welfare Division has trained staff but institutional barriers (their own large case loads, and their client's time limits within the system) to supporting and transitioning adults with an FASD appropriately
- Criminal Justice system has limited training, protocols, and/or ability to recognize and redirect adolescents and adults with an FASD who enter the criminal justice system and belong in other protective kinds of custody

OUTREACH PRIORITIES

- **Transitional, Vocational, and Residential Programs in Nevada:** provide training, protocols, and incentives for working with adolescents and adults with an FASD
- **Social Services Community:** provide training, advocate for FASD to qualify individuals for vocational, transitional, residential, and other disability services
- **Legislature:** provide funding and mandate to Welfare Division and judicial system to hire dedicated social workers for adults with an FASD who can assist adults in meeting requirements, and can advocate for alternative (and appropriate) expectations, self-sufficiency plans, etc.

RECOMMENDATIONS

The Perinatal Substance Abuse Prevention Subcommittee, in collaboration with the Bureau of Family Health Services and legislative representatives, will be developing a Strategic Plan to address the following recommendations. This strategic plan will most likely need to project goals for the next 10 years, and will need to include Measurement Outcomes (and requisite Outputs and Activities) to appropriately identify and evaluate progress made and barriers encountered.

Intervention, from a holistic perspective, would include prevention, interventions at an individual level, and systems' change. The PSAP Subcommittee is uniquely posed to address the system's change that will allow for each of these. PSAP Subcommittee members will prioritize, from within the following list of recommendations, which activities and goals are most deserving of resources based on: 1) feasibility, 2) impact, and 3) ethical imperative.

- ✓ Implement Training and Outreach Programs, and provide "Best Practice" recommendations to Nevada's Health Care Community, School Districts and Bureau of Early Intervention Services, Criminal Justice systems, state-funded child care providers, and transitional, vocational, residential and social service programs serving the disability community.

Health Care Community: Create or identify Consensus Guidelines for identification, referral, and treatment of children, adolescents, and adults with an FASD. Outreach should extend to medical, nursing, and social work schools, organizations providing continuing education, and professional boards and association.

School Districts and Bureau of Early Intervention Services: Create or identify curricula and Best Practices to introduce to Colleges of Education, Special Education teachers and administrators, Early Intervention programs, and School Administrators about FASD, treatment, and Best Practices.

Criminal Justice: Identify curricula and Best Practices appropriate to outreach and education of judges, P.O.S.T. (Peace Officers Standard Training), and medical/mental health professionals within prisons and jails.

Child care Providers: Find existing curricula and Best Practices to work with the State Child Care Development Block Grant administrators to provide mandatory training to Children's Cabinet staff and contract-providers, as well as Nevada Head Start programs.

Transitional, Vocational, Residential and Social Service Programs in Nevada: Create list of the programs and organizations that currently provide services to individuals and families with disabilities; establish a "training calendar" which will accommodate their participation, and provide FASD-specific guidelines. Provide training, protocols, and incentives for working with adolescents and adults with an FASD. Consider requiring state-funded programs that work with the disabled community to demonstrate program modification and development in the area of adults with an FASD.

-
- ✓ Create, train, and support FASD advocacy corps in efforts to enter a variety of systems (at the request of parents/individuals with an FASD) to advocate for informed, lawful, and appropriate system's responses to individuals with an FASD. Systems advocacy and influence should include school districts, Early Intervention, criminal justice, transitional and vocational programs, and social service programs.

School Districts and Bureau of Early Intervention Services: Advocates should work with parents, and within school systems to insure proper adherence (or appropriate filing of complaints) to IEPs and 504 plans.

Criminal Justice: Advocates should work within the criminal justice system to identify alternate sentencing options for adults with disabilities, and represent adults with FASD in determinations of sentencing.

- ✓ Fund and train social workers to function within Welfare, Medicaid, and judicial systems as FASD case managers.

Medicaid: Improve outreach and community awareness of existing programs which may assist families (The Katie Beckett Waiver, Nevada Check Up, etc. (See Appendix D.)

- ✓ Pass amended statutes requiring child welfare agencies and other licensed child placement agencies to investigate the likelihood of prenatal exposure to alcohol and other drugs.
- ✓ Create fellowships for geneticists, pediatricians, and child- and adolescent-psychologists to do rotations with Special Needs children; hire and support the community work (diagnostic assessment) and research of geneticists.
- ✓ Encourage or require state systems of care across the life-span to recognize FASD as a disability.

School Districts and Bureau of Early Intervention Services: Nevada school districts and the Bureau of EIS need to uniformly provide disability status and services for children with an FASD.

Transitional, Vocational, Residential and Social Service Programs in Nevada: Change eligibility requirements in programs designed to assist individuals with disabilities so that IQ cannot be used to disqualify individuals with an FASD.

Legislature: Deem FASD suitable to Special Needs status within Child Welfare agencies (including financial aid to families), Medicaid, and SSI.

- ✓ Legislative allocations of seed monies for four separate projects:

Creation and support of a statewide non-profit whose mission would be to establish an advocacy and education center. Prioritize funding of organization(s) who demonstrate willingness to create Outcome Measures, raise matching funds, look toward model projects on FASD for their own programs, and include parents of children with an FASD on their Board of Directors. Non-profit programs might include: a lending library, a "crisis line," parenting support groups, recruitment and training of family advocates, community training, and a comprehensive referral system.

A pilot project, with outcome measures, which creates a “Center” for FASD Family Services, including assessment and diagnosis, prevention campaigns, referrals and family parenting plans, and training and technical assistance to para-professionals.

Create, fund, and support (through training and technical assistance) a pilot program which works purposefully with children with an FASD, and whose outcomes and experience can be used in the creation and mentoring of other child care programs.

And, the creation and support of FASD Campus for Adolescents and Adults where individuals with an FASD have opportunities to learn, in an appropriate environment, life- and job-skills that allow them to move toward self-sufficiency, and simultaneously allows their care-takers respite.

- ✓ Coordinate a prevention campaign which includes women of child-bearing age, the health care community, Family-Planning organizations, March of Dimes, and pharmacies (where contraception is sold), and high-risk populations (including mothers who’ve already given birth to children with an FASD).

APPENDICES

- Appendix A: Town Hall Meeting Promotional Flyers
- Appendix B: PowerPoint Lecture on Fetal Alcohol Spectrum Disorder
- Appendix C: Testimony Spreadsheet—Grouping of Testimony’s Concerns
- Appendix D: Program Descriptions: The Katie Beckett Waiver, Nevada Check-Up, etc.

Fetal Alcohol Spectrum Disorders (FASD)



Town Hall Meeting on Fetal Alcohol
Spectrum Disorders
January 2006



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence



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www.fasdcenter.samhsa.gov

1-866-STOPFAS (866-786-7327)



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence



SAMHSA FASD Center for Excellence Information Resource Center

- Accessible by phone, mail, or e-mail and through the Web site:
 - › 866-STOPFAS (866-786-7327)
 - › fasdcenter.samhsa.gov
- Service in English and Spanish
- Responds to questions from families, providers, government personnel, academics, researchers, other interested persons
- Connects people with resources



SAMHSA FASD Center for Excellence

Web Site: fasdcenter.samhsa.gov

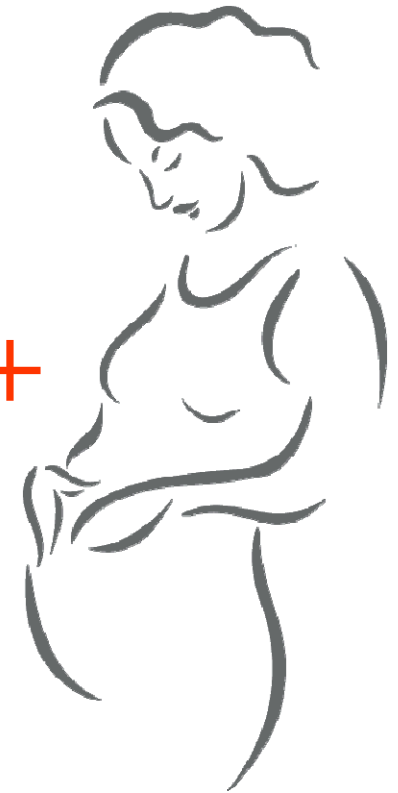
- Searchable database of publications and research on FASD
- Downloadable information
 - › Fact sheets, articles; posters; office cards
- Request form for training and technical assistance
- Downloadable “FASD The Basics” slide show and notes
- Links to national and other FASD web sites

Fetal Alcohol Spectrum Disorders (FASD)

- Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy
- May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications
- Not a diagnosis; no one “has FASD;”
- Someone may have “an FASD”



+



Terminology Used for Diagnosis

Pregnancy



+

Alcohol



May result in



- Fetal alcohol syndrome (FAS)
- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)



FASD: What Do We Know

- Leading known cause of preventable mental retardation
- The majority of individuals with an FASD do not have mental retardation
- The majority of people affected by prenatal alcohol exposure do not have the facial features of FAS
- A fetal alcohol spectrum disorder is often an invisible disability
- 100% preventable
- It can occur in any community where women drink
- Women do not set out to give birth to a child with FAS



FASD: What Do We Know

- An FASD is not a childhood disorder
 - › Prenatal alcohol exposure can cause brain damage
 - › The effects of prenatal alcohol exposure last a lifetime
 - › People with an FASD can do very well in life, especially with the proper recognition and supports
- Alcohol causes more severe neurobehavioral affects than other substances of abuse
- There is no safe time to consume alcohol during pregnancy
- Paternal alcohol use before conception does not cause an FASD
- Not a new disorder



How Much Alcohol Does it Take to Cause Damage?

- There is no way of predicting how much alcohol will cause how much damage for any individual
- There are individual factors such as
 - › How much alcohol is consumed
 - › How the alcohol is consumed
 - › How the alcohol is absorbed
 - › How the alcohol is metabolized by that person
 - › How the fetus will be affected
- Therefore, the only proven safe amount of alcohol to consume during pregnancy is none



Consequences of Not Recognizing an FASD in an Individual

- These individuals often fail with typical education, parenting, treatment, and justice approaches
 - › They often look “normal”
 - › They tend to be very verbal
 - › They say they know what they need to do and don’t follow through
 - › They frequently have average or above average intelligence



Consequences of Not Recognizing an FASD in an Individual

- › Children and adolescents with an FASD are often in foster care, adoptive homes, or with extended family
 - Multiple placements are typical
 - If an FASD is not recognized, they are seen as “NURMU”
 - They often don’t respond as a family’s other children have
 - Foster and adoptive parents often have not been trained to understand how to parent these children
 - These children remain in the foster care system for years
 - At 18 (or before), they are on their own without the supports necessary to succeed in the community
 - They may end up homeless, in jail, or dead



Consequences of Not Recognizing an FASD in a Caregiver

- Caregivers with an unrecognized FASD are often labeled as neglectful, abusive, uncaring, sabotaging, uncooperative, unmotivated, and non-compliant
 - › We take their children away from them
 - › We tell them what they need to do to get their children back
 - We give them multiple instructions regarding treatment, housing, finances, contact with their children, etc.
 - › They say they know what they need to do but they don't follow through on instructions
 - E.g., appointments, treatment, phone calls, visits
 - Especially when we have given them multiple instructions



Consequences of Not Recognizing an FASD in a Caregiver

- The children remain in placement or parental rights are terminated
- Women may have another child with an FASD
 - › They love their children and want a family
- Remember that an FASD is a diagnosis for the family
 - › If a child is identified with an FASD, we must examine the siblings, parents, and possibly other relatives
 - View the whole family as the focus of attention and support



Issues in Accurately Diagnosing an FASD

- If there is a co-occurring FASD with other disorders, the treatment will often be different
 - › Due to the damage to the brain that interferes with proper processing of information
- If the wrong diagnosis is given, the wrong treatments may be prescribed
- If an FASD is not recognized, expectations for the individual may not be appropriate, thus setting the person up to fail
- The only way to get mental health services for the person might be to diagnose a DSM disorder



Typical Difficulties for Individuals With an FASD

- Go off with strangers
- Followers
- Do not complete tasks/chores
 - › Appear to be oppositional
- Repeatedly break the rules
- Don't learn from their mistakes
 - › Don't benefit from natural consequences
 - › Can't anticipate consequences of actions
- Frequently do not respond to point or level systems
 - › Literal in their thinking



Typical Difficulties for Individuals With an FASD

- Problems managing money
- Have difficulty determining what to do in a given situation
- Come across as more intact than they actually are
- Verbal expressive language is often much better than verbal receptive language
- Uneven in school, work, and development
 - › Sometimes they “get it” and sometimes they don’t
 - › They may know something one day but not the next

Strengths of Persons With an FASD

- Friendly
- Likeable
- Verbal
- Helpful
- Caring
- Hard worker
- Determined
- Have points of insight
- Good with younger children*
- Not malicious
- Every day is a new day





How Outcomes Can Be Improved by Recognizing an FASD

- The individual can be recognized as having a disability
- Frustration and anger of providers and families can be reduced by seeing behavior as due to brain damage
- Approaches can be adjusted to meet the needs of the individual and the family
- Families can remain together with the proper supports
- Diagnoses can be questioned



How Outcomes Can Be Improved by Recognizing an FASD

- Multiple admissions for substance abuse treatment can be reduced if brain differences are recognized
- Recidivism in corrections can be reduced
- Long term success can be increased by providing the proper transition and supports
- The quality of life for the individual with an FASD and the family can be dramatically improved
- The sense of accomplishment by providers can be increased resulting in a more positive attitude



Paradigm Shift

“We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed.”

—Dubovsky, 2000



Final Thoughts to Keep in Mind

- When an intervention does not work, it is essential to examine why it is not working that individual at that time
 - › We must determine what we can do to ensure that the person succeeds
- Developing comprehensive systems to address FASD is essential as FASD crosses all systems of care
- FASD is a human issue
 - › Always remember that addressing FASD can be a matter of life or death
 - › **What you do concerning this issue can save lives!**

Testimony Summaries

Defining Issues

Description	# of Person's Emphasizing
Adolescents and Adults with an FASD	
Child supervision of "seemingly normal"/high IQ kids who have aged out of day care and need continued supervision due to FASD	2
Easily led by others into high risk behaviors, unthinking about consequences	3
High risk behaviors include suicide attempts, drug use and abuse, running away, and aggressive outbursts	4
Parents efforts to have children surrounded by positive influences, because a person with an FASD is so easily manipulated and endangered (Difficulty given isolation--misreading social cues, few friends)	3
Children with FASD may not have physical features, may have high IQ--look normal, no diagnosis and so disability remains "hidden" despite their challenges	3
Extensive number of medications taken, adjusted, readjusted (experimenting)	4
Younger Children with an FASD	
Early diagnosis of FAS not particularly helpful as parents have to educate professionals--school systems, psychologists, child behavioral services--about the implications and needs of a child with FASD	3
Parent quitting full-time work (or juggling stressfully) as child's behavior in school (and consequent punishment) as well as "after school hours" needs require more time than a working parent can provide.	6
Worry about what will happen when I'm gone or can't care for him anymore	3
No stranger-awareness, and no boundaries--dangerous.	2
Medical community is not well-educated; parents spend years looking for an appropriate diagnosis, and course of intervention	7
Make work through disability community, with families with children with an FASD part of rotation/Fellowship through med school (children's psychiatry)	
Impulsiveness, lack of sense of consequence, and poor judgement commonly creates situation where individual is perceived as obstinate or deviant, and stigmatized by other children (for poor behavior, and for missed social cues)	4
"No one understands how much trouble this kid is in. . ."	
Importance of Early Intervention and IEP for younger kids	3
Systems Response to Persons with an FASD	

Child not responding to systems in place to support because FASD doesn't allow them to process and respond to reward systems, level systems	2
No FASD programs available in Nevada	3
Nevada is at risk in a way that other states are not: NV geneticist--only person providing "diagnosis" for kids older than 3 in NV sees more FASD in NV than other states (10x more common than Downs) NV has highest per-capita consumption rate (residents, not vacationers) Changes in services have not paralleled increases in population 70% of adopted children have been prenatally exposed 70% women are chronic drinkers 50% of women in child-bearing years drink 50% of pregnancies are unplanned 40% teenagers are 4m pregnant before aware	1
Children suffer because FASD causes Central Auditory Processing Disorder. Oral communication (school, therapy, social services) assumes individual is organizing information and input.	2
"Neurologically Injured" determines every interaction, often unable to meet expectations of schools, peers, employers, parents--but disability doesn't "show." "He tests well, has a high IQ, and gets no services; he knows the difference, and with 2-4 extra hours of homework, he's still failing 1st grade"	2
Teachers aren't educated about FASD (even Special Ed staff), and don't know how to help, or what things are more challenging	7
Clark County School District Special Education not responsive with services, or with seeking to adhere to Best Practices	1
* Resistance to offering testing	1
* Despite educational plan, only offered one of three recommended support services	2
* 504 Plan supposed to allow parents some control, advocacy--routinely ignored	1
IEP (Individual Education Plans) ineffective--multiple, or wrong diagnoses	1
Transitional programs, or after-school programs (for adolescents), and residential programs aren't prepared for these individuals or aren't safe--removal or closure	2
As Foster Parents, received medical assistance for children. Once adopted, most supports disappeared. Once turned 18, all supports disappear (at same time parental insurance stops). Find self becoming my "son's best advocate" so that, because of changes in insurance, or child's age, families don't have to switch doctors and reeducate the professionals	4
Because not autistic, and have an IQ higher than 60, assisted living programs through social services cannot assist. Yet, these individuals cannot live independently. "Change the standard for receiving case management--current eligibility standards are outdated. Cognitive ability above 72 means no supportive community services through the state. "If my son had more problems (diagnosed) we'd get more help"	3

Not fair that because there is no daignosis, he gets a 2ndry diagnosis of "severely emotionally disturbed" to qualify for services"	
Without supportive services, parenting advice, etc. foster children's behavior becomes so out-of-control that they're removed and put into institutional setting	1
Services--Early Intervention--end when child turns three, after which they are dependent upon services through the school district (uninformed and unprepared)	1
Social workers through NV State Welfare Division have worked with adults with an FASD in their population of clients with "barriers to self-sufficiency"	4
Parenting challenges of these individuals not met with CPS services/strategies	
Need help accessing and understanding birth control	
They need mentors and more case management than social workers can provide	4
Welfare's 60 month limit--individuals with an FASD need ongoing support; can't follow-through, have inappropriate boundaries, sense of professionals' time & access, get agitated, lose benefits, and fall through cracks	4
"how would you survive if you rode the bus, but could only remember the last direction you were given?"	
5 cases of recognized FASD: 2 succeeded w/18 months help & transition to family members, 2 into prison system, and 2 unknown (homeless?)	
Significance of a trained professional to help screen for FASD, and develop "work plan"	3
Department of Corrections recently introduced basic prenatal education--most inmates know little about their bodies and health and want to learn. Need education in prison.	1
No data from prisons about this high risk population. We need to incorporate into intake, and educate them	

Suggested Programs and Services

For Parents:

Foster and adoptive parents who don't know the prenatal history of their child at time of adoption	6
Adoption social worker discouraged, knowing that foster parents who do know, and want to pursue assistance will--once adoption is complete--lose financial support, and will find few resources for children with an FASD	
Parenting Classes/Workshops for parents of children with an FASD that are taught by experts, not emphasizing futile parenting techniques for this disability. Real skills & opportunities to Network.	2
Currently parents looking toward therapy models are met by professionals who use cognitive therapy models which won't work. In 9 years of adoption social work, one person had only heard of 1 therapist who appropriately discussed parenting models	1
Supervision and Care setting which allows parents to maintain employment, build a retirement and savings, and provide for children beyond social security and adoption benefits which will end	3
A safety net for parents--someone to call when parents are totally overwhelmed and need immediate help [respite care]	5

Understand prevention as broader than office brochures:	2
Marry prevention to assessment and case management	
Outlaw advertising of alcohol at family events (sports)	
Demand Public Awareness campaign slogan: women of child bearing age should not drink unless they are using birth control.	
Familiarity of our culture with other disabilities--fundraising and education help	

For Children/Adolescents/Adults with an FASD

Addendum or attachment to ID identifying FASD and limited ability to understand implications of Miranda rights, legal representation, etc.	1
Campus-setting for older children with an FASD which provides training and skill development: job skills, money management, daily care issues, medication issues, emotional monitoring, etc. [transitional services]	4
Workshops or Therapy strictly for children with an FASD--skill development, and survival with their limitations (start at early age) [Anger management]	2
Creating system of advocacy--to work with families, schools, courts to educate them and suggest "what is needed" to assist a person with this disability	4
Diagnostic and Treatment services taking a multidisciplinary approach: medical and mental health, educators and parents, community support circles	6
"Community based FASD diagnosis and case management, including teachers, parents, and others.	
"Accountability--referrals for children with an FASD actually go, get services, etc for "seamless diagnosis and case management"	
We need a dedicated clinic where parents can seek diagnosis, and pursue parenting plans and support services	2
Professionally developed materials or place for parents helping with strategies, managing behaviors, and anticipating next stages and next challenges or resources	
Adults with an FASD need a multidisciplinary meeting of all the agencies and people with expectations of them to 1) prioritize how to not lose benefits, and 2) strategize about what supports and systems are needed, and how to function as the "external brain" for this person, without withdrawing assistance.	
Publically funded diagnostic and treatment services, available without delay (9 months to see genetic specialist for diagnosis after psychiatric residential placement)	10
No diagnosis for children over three in Northern NV--Need specialized diagnosis and case management in every community	2
Cannot remove supports--this disability lasts a lifetime	3
We need a children's home where experts can "habilitate" individuals with an FASD and assess chances for mainstreaming	
"If your brain doesn't work, and the system doesn't work, which needs to change?"	
CPS recommends strongly--we need it to provide services, we need it for removals and placements	
"Without diagnosis, they're precluded from services and precluded from support" from school districts, from SSI, from post-adoptive services	

I waited 2 years for diagnosis, and I was able to be a strong advocate."

Remove barriers to prescription medications	1
Stop using the criminal justice systems to "cure brain injury"	2
Require screening before legal proceedings if reasons exist to believe there is FASD	
Educate the Justice System about FASD	
"Is it ethical to put a person with a cognitive disability in prison?"	
Alternate "graduation" --educators pushing for college, because of high IQ	2
Deem FASD a disability--for social security, assisted living, special education help	3
Fund research on FASD, and tie outcomes to the research	1
18 Bed Project in Clark County accessed through welfare: help with parenting, help with cause and effect. Too limited in space and time, but a promising model.	

NEVADA EARLY INTERVENTION SERVICES

FINANCIAL RESOURCES FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS THE KATIE BECKETT WAIVER

The Katie Beckett Waiver/Option

Under 143 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), States are allowed to make Medicaid benefits available to certain children with disabilities who would not ordinarily be eligible for Supplemental Security Income (SSI) benefits because of parents' income or resources. This law is commonly referred to as "The Katie Beckett Waiver" and additional information is available at: www.challenge.net.com/library/files/KatieBeckettWaiver

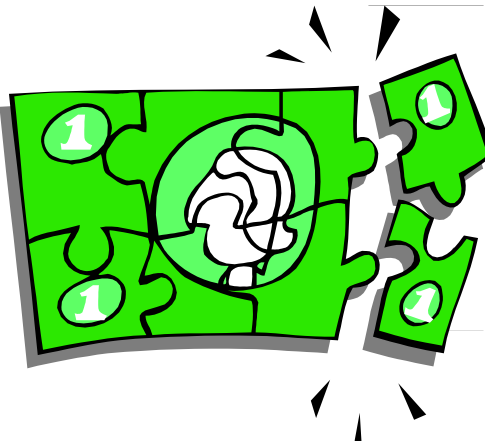
In the past, a parent's income or assets disqualified many children from the Medicaid program. The parents often had little or no private insurance coverage for their child with special needs, but because of the parents assets or income, their child would "fall through the cracks" of the system. The Katie Beckett Waiver (or Option), one of the important parts of the Medicaid program, is helping solve this problem. Under this option, when determining a child's eligibility for Medicaid, a parent's income and assets are counted. However, if a child is severely disabled and meets specific medical guidelines and standards, the child's income and assets are counted and those of the parents may be waived. If the child is then eligible, Medicaid will pay for the same services it does for other children with Medicaid.

If your child qualifies for the Waiver/Option, he or she will get full Medicaid coverage which includes hospital care (in-patient and outpatient), physician care/services, most physician prescribed drugs, eye and dental care, and any other services provided in the home which would normally be provided in a hospital or nursing home. There is a limit of \$150,704.85 per year for psychiatric expenses.

You apply for this program at your local Medicaid office (the phone numbers are listed on the back of this sheet.) Be sure you take school and medical records, verification of income for you and your child, and some verification of the severity of your child's disability to your appointment. Your service coordinator or

Medicaid caseworker can assist you in locating these items if you need help. Like SSI, the Katie Beckett Waiver is retroactive, so apply as soon as you can. This means once your child is made eligible, Katie Beckett will cover medical costs from the beginning of the month you applied in. Even if you think your child might not be eligible because of income or severity of

need — apply. If your application is turned down — start the appeals process. This process is often successful in overturning a denial. At times the waiting list for this waiver is months or years long, so applying early is important!



What is my cost? Generally, if you make less than \$75,000 per year there is no co-payment for families. If your family income is more, then there will be a co-pay, however, if your income is high other factors are considered such as the expenses of owning a business, large debts, and college funds.

How to apply:

- Apply for SSI/Medicaid — when applying for Medicaid, be sure to complete the MABAD (Medical Assistance for the Aged, Blind, and Disabled) portion
- When denied for SSI get a written denial
- At your Medicaid interview ask to be referred to the Katie Beckett program and ask for an application
- When filling out the application, **DO NOT LEAVE ANY BLANKS EMPTY**. Put "N/A" if necessary
- Fill the application out as if your child was completing the application
- Make sure to tell the Medicaid worker that it is a Katie Beckett application

If you have questions about ANY of these programs or services ask your service coordinator to assist you.

Your Service Coordinator May Help You Access The Katie Beckett Waiver/Option

An Eligible Child Must Be:

- Disabled for at least one year (the disability must be severe enough that he or she cannot accomplish without assistance the same things as other children of the same age)
- In need of care that is generally provided in a hospital or nursing home environment (NOTE — your child doesn't have to live in such a facility, just be in need of care that is normally provided in one)
- Be able to live at home (rather than a hospital, nursing home, or other facility) if he or she can get the care needed
- 18 years of age or younger

For children with emotional or behavior problems, the following guidelines apply:

- The child's behavior must be life-threatening, destructive, or disabling to himself or herself or others, characterized by:
 - Active suicidal/homicidal threats, plans or attempts

- Assault, arson, or self-mutilation
- Psychotic depression
- Gross dysfunction resulting in inability to care for him or herself (confusion, disorientation, or memory loss)
- Anorexia nervosa
- Sustained and severe withdrawal from life activities and relationships.

In some cases, a child may qualify for the Katie Beckett Waiver even if he or she is in a residential facility. Talk to your service coordinator or Medicaid caseworker if your child is placed, or is in danger of being placed, in a facility.

Who qualifies for the Katie Beckett Waiver?

- Any child with a disability who does not qualify for SSI
- Any child with a disability who does not have adequate medical coverage or has extra medical costs that the private insurance company does not cover
- Children that cannot move around on their own
- Tube-fed children
- Children that need injections
- A child that is over 3 years and needs to be diapered

Other Medicaid waivers may also be available for your child. Ask your service coordinator for more information or call your local community resource number as listed below.

Nevada Early Intervention Services
3427 Goni Road, Suite 108
Carson City, NV 89706
Toll Free: 1-800-522-0066

Phone: 775-684-3460
Fax: 775-684-3486
www.health2k.state.nv.us/BEIS/

Community Resource Numbers

Carson City	(775) 684-0800
Elko	(775) 738-2531
Ely	(775) 289-1650
Fallon	(775) 423-3161
Hawthorne	(775) 945-3602
Henderson	(702) 486-5000
Las Vegas - Belrose	(702) 486-5000
Las Vegas - Cambridge	(702) 486-6600
Las Vegas - Charleston	(702) 486-5000
Las Vegas - Owens	(702) 486-5000
Las Vegas - Professional Dev. Ctr.	(702) 486-1443
Pahrump	(775) 751-7400
North Professional Dev. Ctr.	(775) 856-8412
Reno Ninth	(775) 688-2200
Tonopah	(775) 482-6626
Winnemucca	(775) 623-6557
Yerington	(775) 463-3028

SERVICE COORDINATOR #: _____

NAME: _____

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NEVADA EARLY INTERVENTION SERVICES

FINANCIAL RESOURCES FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS MEDICAID, NEVADA ✓ CHECK UP

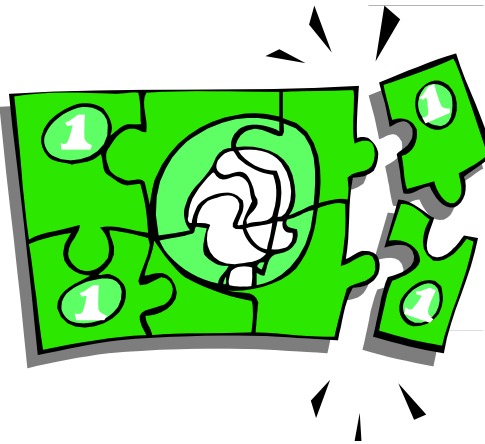
Medicaid is a health care program for people with low incomes and limited assets. The Nevada Department of Human Resources offers medical coverage through a number of programs for individuals and families. Some of this coverage is at no cost to families and some requires a small fee. The services provided may include hospital services, doctor visits, prescriptions, dental care, eye exams and glasses, therapies, and etc.

Some of the ways a family can receive Medicaid benefits include:

- Medicaid coverage for persons who qualify to receive cash assistance (Temporary Aid to Needy Families — TANF). Families may choose to receive medical benefits only.
- Medicaid coverage for persons who cannot receive TANF or assistance through *Nevada ✓ Check Up* due to income from an individual who is not their parent or spouse.
- Emergency medical assistance on a month to month basis for all illegal or other non-citizens not covered in other eligible categories. These applicants must meet TANF or CHAP (Child Health Assurance Program) requirements except for citizenship.
- Medicaid may be provided for the first year of life for any newborn of a Medicaid eligible pregnant woman, regardless of income changes.
- TANF medical coverage is available up to three (3) months prior to the TANF application if the child and family received medical services during this time. Eligibility is determined on a month-by-month basis.
- Medical assistance when TANF ends is available as follows:
 - Medicaid assistance continues for up to twelve (12) months for households which become ineligible for TANF assistance due to increased earned income of the caretaker.

- Medicaid assistance continues for up to four (4) months for households which become ineligible for TANF assistance due to child support collected through the agency.

For more information ask your service coordinator or call the local community resource number on the back of this sheet.



Nevada ✓ Check Up is a State Children's Health Insurance Program that provides affordable, comprehensive health care coverage to uninsured children of low-income families who are not covered by private insurance or Medicaid. The goal of *Nevada ✓ Check Up* is to provide preventive and comprehensive health care coverage for Nevada's uninsured children whose family income is too

high for them to qualify for Medicaid.

Medical Assistance for the Aged, Blind and Disabled (MAABD) is a medical services only program. A person can qualify by being eligible for a public assistance program such as Supplemental Security Income (SSI). Other categories of eligible persons are:

- Disabled children who require medical facility care, but can appropriately be cared for at home (see the Katie Beckett Fact Sheet)
- Aged or physically disabled individuals who require medical facility care, but can appropriately be cared for at home (Home and Community-Based Waivers)
- Certain individuals who have lost SSI eligibility, but would still be eligible if some of their income were disregarded (Public Law Cases)

If you have questions about ANY of these programs or services ask your service coordinator to assist you.

Income Guidelines for Medicaid, *Nevada Check✓ Up*, and the Child Health Assurance Program (CHAP)

Medicaid

Once determined eligible, Medicaid coverage begins from the date you first apply. It is possible to get coverage for the three months prior to your application date. Ask your service coordinator or Medicaid caseworker about this.

The monthly income guidelines to determine eligibility are based on 100% of the federal poverty guideline if the child is over six years, and 133% of the poverty guideline if the child is under six.

Family Size	Poverty Level	
	100%	133%
2	\$ 968	\$1,285
3	\$1,219	\$1,622
4	\$1,470	\$1,956
5	\$1,723	\$2,291

Child Health Assurance Program (CHAP)

The Child Health Assurance Program (CHAP) provides Medicaid coverage to pregnant women and children under age six, including unborns, with income below 133% of poverty; and to children age six or older with income below 100% of poverty. These children are also eligible for "Healthy Kids" services, a program which provides preventive health care such as immunizations, yearly physicals and referrals for health problems of Medicaid eligible infants, children and young adults.

"Healthy Kids" can provide referrals for developmental, dental, vision and/or hearing concerns, as well as family counseling needs.

The following table lists some of the current (11/02) CHAP financial guidelines for the 100% and 133% poverty levels based on monthly income.

Family Size	Poverty Level	
	100%	133%
2	\$1,010	\$1,343
3	\$1,272	\$1,692
4	\$1,534	\$2,040
5	\$1,795	\$2,387

Children born to Medicaid eligible pregnant women are eligible for Medicaid for the first year of life regardless of changes in income level of the family. These children are automatically eligible for the "Healthy Kids" program. If your family is eligible for "Healthy Kids," you may also be eligible for WIC, a food supplement program for women and children. Call your local Community Resource number

(below) or ask your service coordinator for more information.

Nevada Check✓ Up

The current maximum monthly income to qualify for Nevada Check✓ Up is:

Family Size	Income
2	\$1,935
3	\$2,438
4	\$2,941
5	\$3,445

The program does not require the participants to pay co-payments for any services provided, however, quarterly premiums ranging from \$10 to \$50 are charged, based on family size and income. To apply, the head of the household must complete the one page (two-sided) application and must provide proof of income. You may request an application by calling 1-800-360-6044 or ask your service coordinator to help you.

Nevada Early Intervention Services
3427 Goni Road, Suite 108
Carson City, NV 89706
Toll Free: 1-800-522-0066
Phone: 775-684-3460
Fax: 775-684-3460
www.health2k.state.nv.us/BEIS/

Community Resource Numbers

Carson City	(775) 684-0800
Elko	(775) 738-2531
Ely	(775) 289-1650
Fallon	(775) 423-3161
Hawthorne	(775) 945-3602
Henderson	(702) 486-5000
Las Vegas - Belrose	(702) 486-5000
Las Vegas - Cambridge	(702) 486-6600
Las Vegas - Charleston	(702) 486-5000
Las Vegas - Owens	(702) 486-5000
Las Vegas - Professional Dev. Ctr.	(702) 486-1443
Pahrump	(775) 751-7400
North Professional Dev. Ctr.	(775) 856-8412
Reno Ninth	(775) 688-2200
Tonopah	(775) 482-6626
Winnemucca	(775) 623-6557
Yerington	(775) 463-3028

SERVICE COORDINATOR #: _____

NAME: _____

This publication was produced with funds provided through the U.S. Department of Education, Office of Special Education Programs, Part C, Individuals with Disabilities Education Act, Grant #H181A000019

FINANCIAL RESOURCES FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS SUPPLEMENTAL SECURITY INCOME (SSI)

Supplemental Security Income benefits (SSI) is a program that pays monthly benefits to families whose children have certain disabling conditions. To qualify, the family must meet the income eligibility limits.

For children living at home under age 18, Social Security considers the parents' income when deciding if a child qualifies. The local Social Security office decides if the parents' income and assets are within the SSI limits. A team at a state office that includes a disability evaluation specialist and a doctor determine if the child meets Social Security's definition of disabled.

The disability evaluation and determination process generally takes several months. However the law allows for people (including children) whose condition is so severe that they are presumed to be disabled to receive SSI benefits for six months while the formal disability decision is being made. Some of the disability categories in which Social Security will presume the child is disabled and make immediate SSI payments include:

- Blindness
- Deafness (in some cases)
- Cerebral Palsy (in some cases)
- Down Syndrome
- Muscular Dystrophy
- HIV infection

If social security makes these special payments and later decides that your child's disability is not severe

enough to qualify for SSI, the benefits **DO NOT** have to be paid back.

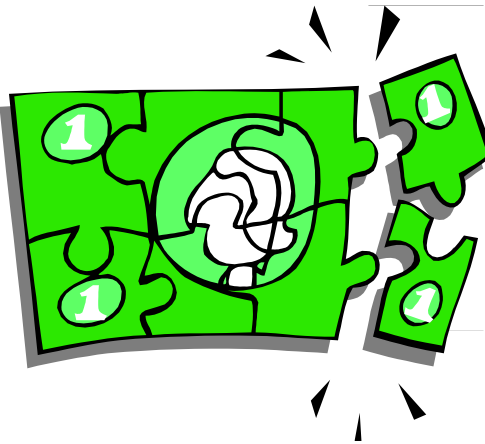
The law says that a child will be considered disabled if he or she has a physical or mental condition (or combination of conditions) that results in "marked and severe functional limitations." The condition must last at least 12 months or be expected to result in the child's death. To determine whether the child's impairment causes "marked and severe functional limitations," the disability evaluation team obtains evidence from a wide variety of sources who have knowledge of your child's condition and how it affects his or her ability to function on a day-to-day basis and over time. These sources may include, but are not limited to, the doctors and other health professionals who treat your child, teachers, counselors, therapists, and social workers.

Most children who qualify for SSI payments will also be eligible for Medicaid, the state program for health care, however this is not automatic and families must apply for Medicaid. The phone numbers for most local Medicaid offices are on the back of this sheet.

For more information or to find the Social Security office nearest you, have your child's social security number available and call toll free: **1-800-772-1213**

TTY Number: **1-800-325-0778**

If you have questions about ANY of these programs or services ask your service coordinator to assist you.



Your Service Coordinator Can Help

Applying for Supplemental Security Income (SSI) Benefits

To apply for SSI benefits for your child, call or visit your local Social Security office. You can find the office nearest you by calling, toll free: **1-800-772-1213** or visit their website at www.ssa.gov. Your early intervention service coordinator can help you with this if you have a problem.

Have your child's birth certificate and social security number available, as well as records showing your child's and family's income and assets. The medical evaluation specialists at Disability Determination Service (DDS) need thorough and detailed medical records to help them decide if your child is disabled. You can speed up this process by providing the medical records or helping Social

Security get them. When you apply for benefits, you will be asked to provide the names, addresses, and telephone numbers of all the doctors, hospitals, clinics, and other specialists your child has seen.

You will also be asked to describe how your child's disability affects his or her ability to function on a day-to-day basis. Therefore, Social Security may ask you to provide the names of early intervention professionals, child care providers, and other family members who might also spend time with your child, such as grandparents, who can share information about your child's abilities and challenges. Your early intervention records might also be helpful and your service coordinator can help you get

a copy to take with you to the interview. Be as specific and complete with your answers as possible. If you do not have all the information, tell the interviewer as much as you know.

Children with Special Health Care Needs (CSHCN)

If a child is disabled and eligible for SSI, they are also referred for health care services under the Children with Special Health Care Needs (CSHCN) program. In Nevada this program is administered by the Division of Health and provides specialized health care services. Even if your child is not eligible for SSI, the CSHCN program may be able to help your child. Your service coordinator can help you contact this program as well.

Please Note: Most of the information on this fact sheet comes from Social Security Administration Publication No. 05-10026.

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